

# P ERVASIVE DEVELOPMENTAL DISORDERS

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## **Introduction**

Pervasive Developmental Disorders (PDDs) is a classification used to describe disorders arising during the first years of life which disrupt various developmental processes (National Dissemination Center for Children with Disabilities, 2001). The diverse expression of symptoms that accompany PDDs may challenge clinicians in diagnosis and treatment. Although children with these conditions may present for evaluation and treatment at any point in the life cycle, parents usually note symptoms as early as infancy; typically onset is prior to three years of age (National Institute of Neurological Disorders and Stroke [NINDS], 2001). PDDs vary from the majority of recognized mental disorders which generally appear in late adolescence or early adulthood (Volkmar, 1999).

Symptoms of PDDs include communication problems, such as: using and understanding language; difficulty relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings; and repetitive body movements or behavior patterns (NINDS, 2001). Table 1 presents the most common characteristics of PDDs.

Children diagnosed with this class of disorders may also exhibit the following characteristics: impairments in social interaction, imaginative activity, and both verbal and nonverbal communication skills; participation in activities that tend to be repetitive, and a limited range of interests.

Table 1

### Characteristics of Pervasive Development Disorders

Impairment in social interaction skills;  
Impairment in communication skills; or  
Presence of stereotyped behavior, interests, and activities.

Source: National Information Center for Children and Youth with Disabilities, January 1998.

Autism is often referred to as a "spectrum disorder," meaning that the symptoms and characteristics of autism can present themselves in a variety of combinations, ranging from extremely mild to quite severe (Autism Spectrum Disorders, 2002). Autism is also referred to as autism spectrum disorders (ASDs), according to the American Academy of Pediatrics to define the broader spectrum of clinical characteristics that now define autism (American Academy of Pediatrics [AAP], 2007). PDD may also be referred to as ASD and the terms may be used interchangeable (National Institute of Mental Health [NIMH], 2007).

Table 2 identifies all of the umbrella PDD categories, according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*. Two of these—Autistic Disorder and Asperger's Disorder—are covered in this section. Persons needing information on Childhood Disintegrative Disorder and Rett's Disorder, which have a low incidence in children, should research current literature.

Table 2

### Types of Pervasive Development Disorders

- AUTISTIC DISORDER
- ASPERGER'S DISORDER
- RETT'S DISORDER
- CHILDHOOD DISINTEGRATIVE DISORDER
- PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED

Source: National Institute of Neurological Disorders and Stroke (NINDS), 2001.

## Causes and Risk Factors

PDDs are believed to be caused by neurological differences that have yet to be fully explained (Stanford University School of Medicine, 2002). Currently, researchers are investigating areas such as neurological damage and biochemical imbalance in the brain. It is understood that these disorders are not caused by any psychological factors (NICHCY, 2001). Although a number of different theories have been put forward, none has withstood close scrutiny. Probably several causes and etiological pathways lead to PDD. There is no reason to suppose there is only one pathway.

Ten years ago, commonly accepted incidence rates ranged from 5-15 individuals per 10,000 (Stanford University School of Medicine, 2002). Today, projected incidence rates range anywhere from 7 to 48 per 10,000 (Stanford University School of Medicine). There also appears to be a gender difference in autism, with four times more males than females being diagnosed. Autism affects individuals across all racial, ethnic and social groups. Table 3 illustrates these incidence rates.

Table 3

### Incidence of Pervasive Development Disorders

- 1 in 1,000 individuals diagnosed with the "classic" autism;
- 1 in 500 individuals within the autism spectrum, including PDDs; and
- 1 in 200 individuals within the autism spectrum, including PDD and Asperger's.

Source: National Autism Society of America Conference, Dr. Marie Bristol-Powers from the National Institute of Child Health and Human Development, as cited by the Autistic Children's Activity Program, 2002.

## Categories

Each of the PDDs has specific diagnostic criteria as outlined by the American Psychiatric Association in its *DSM-IV*. Although the term *pervasive development disorders* was introduced well over a decade ago, it is unfamiliar to lay people, as well as policy makers and health administrators (Rimland, 1993). Rimland notes that classifying these disorders as PDDs may prove to be confusing due to the fact that autism is a specific (rather than pervasive) disorder characterized by deficits in social and cognitive functioning. There is, however, a need for a classification title due to the fact that most children have some form of PDD, rather than being diagnosed specifically with autism or Asperger's Disorder (Rimland).

The intent of the *DSM-IV* is that the diagnostic criteria not be used as a checklist, but rather as a guideline for diagnosing pervasive developmental disorders. There are no clearly established guidelines for measuring the severity of a child's symptoms. In many situations, it is difficult to isolate the characteristics of autism from a PDD not otherwise specified (PDDNOS) (Boyle, as cited in the NICHCY, 2001). Accordingly, a child may be diagnosed by one practitioner as having autistic disorder and by another as having PDDNOS.

Generally, a child is diagnosed as having PDDNOS if he has have some behaviors seen in autism, but does not meet the full *DSM-IV* criteria for having autistic disorder (NICHCY, 2001). Although the terminology and diagnostic process for these disorders can be confusing, treatment of the child will be consistently based on his diagnosis.

Table 4 outlines major points which help distinguish the difference between the specific diagnoses.

## AUTISTIC DISORDER

Autistic disorder is the most common of the PDDs. Manifestations of the disorder vary greatly, depending on the developmental level and chronological age of the individual (NICHCY, 1998).

By definition, the onset of autistic disorder is prior to age three years and it follows a continuous course (NICHCY, 1998). In school-age children and adolescents, developmental gains in some areas are common, e.g., increased interest in social functioning as the child reaches school age. Some individuals deteriorate behaviorally during adolescence, whereas others improve (NICHCY).

The essential features of autistic disorder are the presence of markedly abnormal or impaired development in social interaction (Murphy, 2001). Older children may fail to develop nonverbal forms of communication and do not have interest in forming friendships. There may be a lack of sharing, enjoyment, interests, or achievements with other people (NICHCY, 1998).

Table 4

### Distinguishing Characteristics of Pervasive Developmental Disorders

- **AUTISTIC DISORDER** - Impairment in social interaction, communication, and imaginative play prior to age three years. Stereotyped behaviors, interests and activities.
- **ASPERGER'S DISORDER** - Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.
- **PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED** (commonly referred to as atypical autism) - a diagnosis of PDDNOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.
- **RETT'S DISORDER** - A progressive disorder which, to date, has occurred only in girls. Characterized by a period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands, replaced with repetitive hand movements beginning at the age of 1-4 years.
- **CHILDHOOD DISINTEGRATIVE DISORDER** - Characterized by normal development for at least the first two years, significant loss of previously acquired skills.

Source: American Psychiatric Association, as cited by the Autism Society of America, 2002.

There is an increased risk of autistic disorder among siblings of individuals with the disorder. Rates of the disorder are four to five times higher in males than in females (*DSM-IV*, as cited in the PDD Support Page, 2000). Females with the disorder are more likely, however, to exhibit more severe mental retardation (NICHCY, 1998).

The number of reported autism cases has increased by 173% in the past decade, according to the Autism Program of Virginia (Associated Press, 2003). In Virginia, the incidence of autism from 2000 to 2004 increased by 78% (Associated Press).

Table 5

### Prevalence of Autism

- Autism affects an estimated 1 in 150 births.
- It is estimated that as many as 1.5 million Americans today have a form of autism.
- Autism is growing at a rate of 10-17% a year.

Source: Autism Society of America, 2002.

### Diagnosis

There are no medical tests for diagnosing autism, thus an accurate diagnosis must be based on observation of the child's communication, behavior, and developmental levels (Autism Society, 2002). However, because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited (Murphy et al., 2001).

In October 2007, the American Academy of Pediatrics (AAP) issued a report to assist providers in the early detection of autism. Children with autism demonstrate distinct deficits, and recognition of these symptoms may aid providers in the assessment of autism. Language delays, usually around 18 months of age, may be the first issue that prompts parents to consult their child's pediatrician (American Academy of Pediatrics, *Identifying Infants and Young Children with Developmental Disorders in the Medical Home*, 2006). There are very subtle signs that may actually lead to earlier diagnosis. These, according to the AAP, include:

- not turning when the parent says the child's name;

- not turning to look when the parent points says, “Look at...” and not pointing to themselves to show parents an interesting object or event;
- lack of back and forth babbling;
- smiling late; and
- failure to make eye contact with people.

According to the AAP, *Identifying Infants and Young Children with Developmental Disorders in the Medical Home* (2006), warning signs that warrant immediate evaluation include:

- no babbling or pointing or other gestures by 12 months,
- no single words by 16 months,
- no two-word phrases by 24 months; and
- regression or loss of language or social skills at any age.

Children with ASDs demonstrate deficits in social relatedness and do not appear to seek connectedness (AAP, *Identifying Infants and Young Children with Developmental Disorders in the Medical Home*, 2006). Because children with ASDs lack fundamental social skill building blocks, they may be less likely to develop age appropriate relationships. Proper assessment allows for early intervention.

Further, the AAP has issued a policy statement that recommends that all children be screened for autism during their regular doctor's visits at 18 months and 24 months (2006). Since the characteristics of the disorder vary, a child who exhibits symptoms of ASD should also be evaluated by a multidisciplinary team, which may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or another professional knowledgeable about autism (Autism Society of America, 2002).

Identifying children who have or who may develop autism is difficult (Barclay, 2004). Table 6 outlines the diagnostic criteria for autistic disorder.

Children who have positive screening results should be referred to early developmental intervention and early childhood services and scheduled for earlier return visits to increase developmental observation (AAP, 2006).

### ***Causes and Risk Factors***

Uncertainty surrounding the etiology of autism has stalled primary prevention efforts (Newschaffer, 2003). Previous studies have focused on the genetic aspect of autism; however, gene-finding studies are far from congruent and no model has yet explained the gender disparity and variable phenotype across family datasets (Newschaffer).

Possible nonheritable risk factors are pre- and perinatal maternal infections, birth complications, chemical exposure, and childhood vaccinations (Newschaffer, 2003). Maternal infections and birth complications associated with autism has been reported with some consistency (Newschaffer). Most recently, attention has been focused on childhood immunizations being associated with autism (Newschaffer). Three expert studies released in 2000-2001 have concluded that the data available did not support a link between the Measles-Mumps-Rubella (MMR) vaccination and autism (Newschaffer).

Table 6

### Diagnostic Criteria for Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
    - a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
    - b) failure to develop peer relationships appropriate to developmental level;
    - c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);
    - d) lack of social or emotional reciprocity;
  2. Qualitative impairments in communication as manifested by at least one of the following:
    - (a) delay in or total lack of development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
    - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
    - (c) stereotyped and repetitive use of language or idiosyncratic language
    - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level;
  3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
    - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals;
    - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements);
    - (d) persistent preoccupation with parts of objects;
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: American Psychiatric Association, 1994, as cited in NICHCY.

Another recent study tested the levels of testosterone in the amniotic fluid and the impact these levels may have on the social development of a child (Lutchmaya, 2002). The study has identified a link between prenatal hormones and social development (Lutchmaya). The findings have implications for understanding abnormal conditions of social development, such as autism (Lutchmaya).

A study from Heidi Larsson and colleagues in Denmark determined that premature births and pregnancy complications are associated with an increased risk for developing autism (Kaiser Family Foundation, 2005).

As shown in Table 7, a study at the University of Western Australia by Emma J. Glasson, Ph.D., has shown an association between difficult births and the development of autism later in life (DeNoon, 2004). Not every autistic child had a difficult birth but, as a group, autistic children have had more birth complications than other children (DeNoon). Some of the birth problems associated with autistic children include: near-miscarriage; induced labor; labor of less than one hour; fetal distress; and Cesarean section (DeNoon). Also, as a group, the mothers of autistic children give birth at an older age (DeNoon). The study stresses that these factors did not cause autism (DeNoon).

*Table 7*

### **Autism Associated with Premature Births and Pregnancy Complications**

- Infants born before 35 weeks gestation, as opposed to 37 to 42 weeks gestation, are 2.5 times more likely to be diagnosed with autism.
- Infants born in a breech position are 1.63 times more likely to be diagnosed with autism.
- Infants who score 7 or lower on the Apgar test, composite test to measure heart rate, respiratory effort, muscle tone, skin color and reflex irritability five minutes after birth are 1.89 times more likely to develop autism.
- Infants born to parents with no psychiatric disorder history are 3.41 times less likely to develop autism.
- There is a significant association between high parental age (over 30 for the mother and 35 or older for the father) and autism.

Source: Henry J. Kaiser Family Foundation, 2005.

Another study conducted by a team of brain scientists at Carnegie Mellon University has discovered findings which led to the “Underconnectivity Theory,” which states that autism is a system-wide brain disorder that limits the coordination and integration among different areas of the brain (The PEATC Press, 2004). This suggests treatment of autism as a system-wide disorder, rather than for a localized region or particular area of the brain (The PEATC Press).

### ***Comorbidity***

Research has revealed that autism has familial links with other mental disorders, notably depression, obsessive-compulsive disorder, and motor tics (The Chemical, Industrial & Pharmaceutical Laboratories [CIPLA], 2000). Depression is more frequent in immediate relatives and pre-dates the arrival of the child with autism. However, its occurrence is linked to the development of depression in the child with autism. It may appear that some children with autism appear to have mental retardation, language disorders or even congenital deafness or blindness and these conditions do co-occur with autism (Murphy et al., 2001). Epilepsy occurs in up to 30% of those with autism and can amplify their symptoms. Research has been conducted which suggests that epilepsy might cause or mimic autism (CIPLA).

### ***General Treatment Principles***

Due to the severity of autistic disorder, the need for a high level of service, and corresponding high costs, there has been a continuing search for effective treatments. The goal of treatment for autistic disorder is to promote the child’s social and language development and minimize behaviors that interfere with the child’s functioning and learning (U.S. Department of Health and Human Services, 1999). Intensive special education programs that are sustained over time and behavior

therapy implemented early in life can aid the autistic child in acquiring language and other learning. Special education programs in highly structured environments also aid the patient in gaining social and job skills. Only recently have studies shown positive outcomes for very young children with autism (U.S. Department of Health and Human Services).

### ***Treatment Guidelines***

Although there is no proven treatment for autism, research has demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior (U.S. Department of Health and Human Services, 1999). Because of the spectrum nature of autism and the many behavioral combinations which can occur, no one approach is effective in alleviating symptoms of autism in all cases.

The goals of treatment for autism are to improve language and social skills, decrease problem behaviors and to support parents and families (Prater & Zylstra, 2002). Early intervention for treatment of autistic children is critical, given that children who begin treatment at a young age have significantly better outcomes (Prater & Zylstra).

The treatment information discussed in the following paragraphs has been compiled by the Autism Society of America (2002).

Studies show that individuals with autism respond well to a highly structured, specialized education program, tailored to their individual needs. A well-designed intervention approach may include some elements of communication therapy, social skill development, sensory integration therapy and applied behavior analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some children with autism may be best addressed by a structured education and behavior program which contains a one-on-one teacher to student ratio or small group environment. However, many other children with autism may be successful in a fully inclusive general education environment with appropriate support. In addition to appropriate educational supports in the area of academics, students with autism should have training in functional living skills at the earliest possible age.

To be effective, any approach should be flexible in nature, rely on positive reinforcement, be re-evaluated on a regular basis, and provide a smooth transition from home to school to community environments. A good program will also incorporate training and support systems for parents and caregivers, with generalization of skills to all settings.

### ***Promising Treatments***

The following section is a summary of the treatments highlighted by Families for Early Autism Treatment, Inc. which show promising results in the treatment of autistic disorder in children.

### **Educational Implications**

Early diagnosis and appropriate educational programs are important to children with autism or PDD (NICHCY, 1998). From the age of three, children with autism and PDD are eligible for an educational program appropriate to their individual needs. Behavior and communication problems that interfere with learning frequently require the assistance of a knowledgeable professional in the autism field who develops and helps to implement a plan which can be carried out at home, and school (Autism Society of America, 2002).

### **Educational and Communication Focused Interventions**

The TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren) approach recognizes differences in the rate and nature of development among children.

Teaching objectives are based on individual developmental patterns. The guiding principles of the TEACCH program are to provide strategies that support the person throughout the lifespan; facilitate autonomy at all levels of functioning; and accommodate such strategies to accommodate individual needs.

The AAP emphasizes the need for effective educational interventions. The components that should be included are listed in Table 8.

*Table 8*

### **Effective Early Childhood Intervention for Children with ASD**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Entry into intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made;</li> <li>• Provision of intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives;</li> <li>• Low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualized goals;</li> <li>• Inclusion of a family component (including parent training as indicated);</li> <li>• Promotion of opportunities for interaction with typically developing peers to the extent that these opportunities are helpful in addressing specified educational goals;</li> <li>• Ongoing measurement and documentation of the individual child's progress toward educational objectives;</li> <li>• Resulting in adjustments in programming when indicated;</li> <li>• Incorporation of a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions;</li> <li>• Implementation of strategies to apply learned skills to new environments and situations (generalization) and to maintain functional use of these skills; and</li> <li>• Use of assessment-based curricula that addresses:             <ul style="list-style-type: none"> <li>- functional, spontaneous communication;</li> <li>- social skills, including joint attention, imitation, reciprocal interaction, initiation, and self-management;</li> <li>- functional adaptive skills that prepare the child for increased responsibility and independence;</li> <li>- reduction of disruptive or maladaptive behavior by using empirically supported strategies, including functional assessment;</li> <li>- cognitive skills, such as symbolic play and perspective taking; and</li> <li>- traditional readiness skills and academic skills as developmentally indicated.</li> </ul> </li> </ul> |
|---|

Source: American Academy of Pediatrics (AAP), *Management of Children with Autism Spectrum Disorders*, 2007.

### **Natural Language Methods**

Significant gains for teaching language, including speech intelligibility, have occurred in recent years. Speech and language pathologists often integrate communication training with the child's behavior program to provide a coordinated opportunity for structured and naturalistic language learning. The chief focus of skill development for children with autism is communication, because it is the most pervasive area of developmental delay. Instruction in communication is designed to provide a generative tool that will serve many immediate needs throughout the child's life.

### **Picture Exchange Communication System**

The Picture Exchange Communication System (PECS) is a communication-training program that helps children with autism acquire functional communication skills. Children using PECS are

taught to give a picture of a desired item to a communication partner in exchange for the item, thus initiating a communicative act for an actual outcome.

### **Behavior Intervention**

Effective treatment for severe behavioral disorders requires early intervention for many years, during all or most of the child's waking hours, addressing all significant behaviors in all of the child's environments by all significant persons (Lovaas, as cited by the Autism Society of America, 2002). This best describes the basic idea of intensive behavior intervention, which has as its goal teaching the child how to learn by focusing on developing skills in attending, imitation, receptive/expressive language, pre-academics, and self-help. However, this method has been controversial and the research findings have been considered by some to be difficult to replicate (Mudford et al., as cited by Elder, 2002).

There is some evidence to support both traditional and newer naturalistic behavioral approaches to teaching social skills. Joint attention training may be especially beneficial in young, preverbal children. A recent study demonstrated that joint attention and symbolic play skills can be taught (AAP, *Management of Children with Autism Spectrum Disorders*, 2007). Because joint attention behaviors precede social language development, joint attention behavior training, which uses a behavior modification approach, shows promise for teaching children with autism behavioral skills (AAP, *Management of Children with Autism Spectrum Disorders*). Social skills groups, social stories, visual cueing, social games, video modeling, scripts, peer-mediated techniques, and play and leisure curricula are supported primarily by descriptive and anecdotal literature, but the research-based literature is increasing (AAP, *Management of Children with Autism Spectrum Disorders*).

### **Occupational Therapy and Sensory Integration Therapy**

The information in the following section is taken from the AAP's *Management of Children with Autism Spectrum Disorders* (2007). While occupational therapy is helpful in the development of self-care skills, such as dressing, using utensils, personal hygiene and academic skills, it also shows promise in the promotion of play skills and the establishment of routines to improve attention and organization in children with ASD. While research regarding the efficacy of occupational therapy in ASD is lacking, sensory integration (SI) therapy often is used alone or as part of a broader program of occupational therapy for children with ASDs. The goal of SI therapy is to correct deficits in neurological processing and integration of sensory information to allow the child to interact with the environment in a more adaptive way. Studies are being conducted; to evaluate the effectiveness of SI. SI may be helpful as part of an overall program that uses desired sensory experiences to reinforce a desired behavior and to assist with transitioning between activities.

### **Pharmacological Treatments**

The information in the following paragraph is taken from the AAP's *Management of Children with Autism Spectrum Disorders* (2007). Pharmacologic interventions for children with ASD may be considered for maladaptive behaviors such as aggression, self-injurious behavior, repetitive behaviors, sleep disturbance, anxiety, hyperactivity, inattention, destructive behavior, or other disruptive behaviors. After treatable medical causes and environmental factors have been ruled out, medication may be considered if the behavioral symptoms cause significant impairment in functioning. In some cases, the diagnosis of a comorbid disorder can be made and the child may be treated with medications that are used for treating these conditions. Modifications of diagnostic criteria may be necessary to account for clinical presentations of psychiatric conditions in individuals with developmental disabilities.

Antipsychotic medications are often used to treat severe aggression exhibited by children with autism. Numerous controlled clinical trials cited by Elder (2002) and referred to in this section have shown that various types of antipsychotics are efficacious in treating hyperactivity, excitability, and stereotyped behaviors. Psychostimulants have also been used for years to treat the hyperactivity and inattention common in autism. Of all pharmacological information reviewed, the findings associated with psychostimulant trials and the reports of clinicians and families are mixed. However, studies have shown that many children with autism who present with extreme hyperactivity do benefit from psychostimulants, although individual reactions vary greatly, and many families oppose using these medications.

Serotonin-affecting medications have been shown to be effective in treating symptoms of autistic disorder and have shown to be effective in reducing self-injury, increasing socialization, and decreasing anxiety. It has been estimated that 80% of the psychopharmacological interventions used to treat children have unfortunately not been empirically tested on children (Riddle et al., as cited by Elder). It is not surprising that there are questions about the use of these interventions. A more detailed discussion of the use of antidepressants in treating children and adolescents is included in the “Antidepressants and the Risk of Suicidal Behavior” section of the *Collection*.

### ***Unproven Treatments***

The understanding of autism has grown tremendously. Although there is no cure, increased knowledge about the disorder has led to the development of better treatments. Because of the rising prevalence of autism, more research is needed to increase knowledge about effective treatment interventions.

The following are treatments for which there is conflicting data regarding effectiveness.

Auditory integration training	Antifungal medications
Facilitated communication	Detoxication; chelation
Hyperbaric oxygen	Dietary manipulations, e.g. elimination of gluten, casein
Secretin	Hippotherapy; dolphin therapy
Vitamin B6 and magnesium	Sensory integration therapy
Dimethylglycine (DMG)	Craniosacral therapy
Intravenous immunoglobulin (IVIG)	Behavioral optometry
AZT (zidovudine, Retrovir)	Steroids

Source: Kallen, R., 2000.

Chelation therapy—a series of intravenous infusions containing ethylenediaminetetraacetic acid (EDTA) and various other substances—is another unproven treatment option for autism (National Council Against Health Fraud, 2002). Chelation therapy causes heavy metals, such as mercury, to bind to the chelation, thus causing its removal from the body (Tilton, 1998). In theory, once the mercury has been removed, the effects of the toxin are eliminated (Tilton). To date, there has been no well-designed research to show that chelation is successful in the treatment of autism (National Council Against Health Fraud). Using chelation, as opposed to a proven treatment, can result in fatalities (National Council Against Health Fraud).

The American Academy of Pediatrics acknowledges prevalence in the utilization of nonstandard therapies in the treatment of autism. Accordingly, it is important that providers become knowledgeable about complementary and alternative medicine therapies (CAM) (AAP, *Management of Children with Autism Spectrum Disorders*, 2007). Providers should avoid becoming defensive or dismissive of CAM and instead help families understand how to evaluate scientific evidence and recognize unsubstantiated treatments (AAP, *Management of Children with*

*Autism Spectrum Disorders*). Providers should evaluate the scientific evidence of effectiveness and risk of harm and convey this information to the families, just as one should for treatment with medication and for non-medical interventions (AAP, *Management of Children with Autism Spectrum Disorders*). An example is the utilization of a gluten-free/casein-free diet for children. While there is no evidence to support or refute this intervention, studies are currently underway. These studies will provide useful information regarding the effectiveness of these CAM (AAP, *Management of Children with Autism Spectrum Disorders*).

## **ASPERGER'S DISORDER**

Asperger's Disorder is a type of PDD characterized by problems in development of social skills and behavior (American Academy of Child & Adolescent Psychiatry [AACAP], *Facts for Families, Asperger's Disorder No. 69*, 1999). Asperger's is commonly recognized after the age of three (National Institute of Neurological Disorders and Stroke [NINDS], 2001). In the past, many children with Asperger's Disorder were diagnosed as having autism or other disorders. While autism and Asperger's have certain similarities, there are several important differences (AACAP).

Clinically, the difference between autism and Asperger's Disorder is based upon the severity and in the qualitative expression of the criteria (Bloch-Rosen, 1999). Both syndromes are characterized by social interaction deficits, impaired communication skills, and unusual or bizarre behaviors (Frith, as cited in Bloch-Rosen, 1999). However, motor deficits are more pronounced in Asperger's Disorder and its onset is later, with the child exhibiting social skill deficiencies without grossly impaired language skills (Frith, as cited in Bloch-Rosen). Additionally, children with Asperger's Disorder may exhibit a variety of characteristics, and the disorder can range from mild to severe. Children may also have difficulties with change and prefer sameness (Kirby, 2001). Other symptoms include sensitivity to sounds, tastes, smells, and sights, a preference for soft clothing and certain foods, and intolerance to certain sounds or lights (Kirby).

Asperger's Disorder was not added to the *DSM-IV* until 1994 and only in the past few years has it been recognized by both professionals and parents (Kirby, 2001). Of all of the PDDs included in the *DSM-IV*, Asperger's Disorder has been the most debated (AACAP, 1999). Today, children diagnosed with Asperger's would have been diagnosed with autism prior to its addition in the *DSM-IV*. The *DSM-IV* classification defines Asperger's on the basis of the presence of qualitative impairments in social interaction like those observed in autism, but without the significant delay in language or cognitive behavior (AACAP).

### ***Diagnosis***

Diagnosis of Asperger's Disorder requires the participation of professionals with different areas of expertise. Klin & Volkmar (1995) have stated that this is particularly true with overall developmental functioning, neuropsychological features, and behavioral status. Accordingly, clinical assessment is most effectively conducted by an experienced interdisciplinary team. In the majority of cases, a comprehensive assessment will involve the following components: history; psychological assessment; communication and psychiatric assessments; further consultation as needed; parental conferences; and recommendations. Also, due to the lack of awareness many service providers may have about Asperger's Disorder, it is beneficial for evaluators assessing the child to maintain contact with the professionals who are responsible for obtaining and employing the treatment interventions.

It is important to encourage parental participation in the evaluation of the child in order to demystify the assessment procedures and to make parents an integral part of the assessment and

treatment planning. At this time, parents can be informed and educated about the lack of knowledge about Asperger's Disorder and the confusion surrounding the disorder.

### ***Comorbidity***

There are few studies regarding co-morbid psychiatric disorders with children diagnosed with Asperger's Disorder. However, research has shown an association between Asperger's Disorder and Tourette's Syndrome (Bloch-Rosen, 1999). Comorbidity of certain conditions may vary according to the child's developmental level. For example, Attention Deficit Hyperactivity Disorder (ADHD) appears to be more common in younger children diagnosed with Asperger's Disorder, while depression may be more apt to emerge in adolescence (Bloch-Rosen). Children with Asperger's Disorder are also at risk for other psychiatric problems, including schizophrenia (AACAP, 1999). Mental retardation is not usually observed in children diagnosed with Asperger's Disorder (AACAP).

Other disorders which may co-occur with Asperger's Disorder include obsessive-compulsive disorder, depression, and ADHD (Bloch-Rosen, 1999). Obsessive behavior and restrictive interests are both characteristics of Asperger's syndrome, which can make it difficult to distinguish between Asperger's and other disorders which are also characterized by obsessive-compulsive behaviors (Blacher et al., 2003).

Children with Asperger's have also been identified as having postural instability and motor clumsiness (Blacher et al., 2003). Children with Asperger's can also have silent and independent reading levels below grade level and exhibit problems answering inferential comprehension questions (Blacher et al.).

### ***General Treatment Principles***

Because of the scarcity of research on interventions, there are no evidence-based practices available for treating children with Asperger's Disorder. However, there are guiding principles which may be offered, based on informal observations made by experienced clinicians, intervention strategies used with individuals with high-functioning autism, and suggested interventions for individuals with Nonverbal Learning Disabilities syndrome (Klin & Volkmar, 1995).

Treatment for Asperger's, as for all PDDs, should be focused and individualized in order to appropriately relate to the full range of impairments (AACAP, *Facts for Families, Asperger's Disorder No. 69*, 1999). Treatment planning should include provisions for structured opportunities for learning, along with appropriate generalization of what is being learned in order to ensure comprehension (AACAP).

Specific intervention, including teaching practices and approaches, behavioral management techniques, strategies for emotional support, and activities intended to foster social and communication competence, should be conceived and implemented in a thoughtful, consistent and individualized manner (Klin & Volkmar, 1995). It is critical to involve parents in the intervention process along with other social agents (Blacher et al., 2003). Recently, success has been shown in training parents to manage the behavior of children with Asperger's Disorder (Blacher et al.).

### ***Promising Treatments***

The following is a summary of the treatments indicated to have promising results for children having Asperger's Disorder.

### **Educational Interventions**

Educational interventions are necessary in treating a child with Asperger's Disorder. Moreover, because securing educational and related services may be difficult due to lack of knowledge about Asperger's, the parents and clinician should work closely together to supply the child and school personnel with the necessary information and help.

Because these children generally do well with memory tasks, teaching in a rote fashion may help the child to retain the information presented (National Alliance for the Mentally Ill [NAMI], 2002).

The most important component of the educational curriculum and treatment strategy involves enhancing communication and social competence (Klin & Volkmar, 1995). Accordingly, the curriculum content for the child should be decided based on long-term goals, so that the utility of each element is evaluated in terms of its long-term benefits for the child's socialization skills, vocational potential, and quality of life.

### **Behavior Management**

Children with Asperger's exhibit various challenging behaviors. Therapeutic and educational strategies can be beneficial, and training is favorable for assisting the child in recognizing troublesome behaviors (Klin & Volkmar, 1995). Setting appropriate limits in dealing with problematic behaviors such as obsessive behavior, excessive interrupting, or any other disruptive behavior can also be very effective. Moreover, because a child with Asperger's Disorder may require assistance with making safe and appropriate choices, behavior management techniques teach the child how to consider alternative actions (Klin & Volkmar).

As children diagnosed with Asperger's Disorder age, they may demonstrate symptoms of despondency, negativism, and clinical depression due to their feelings of inadequacy in social situations and failures in maintaining relationships (Klin & Volkmar, 1995). Practicing communication and social skills prepares the child to deal with social and interpersonal expectations. This, in turn, enhances the possibility of establishing friendships (Klin & Volkmar).

### **Psychotherapy**

Although insight-oriented psychotherapy has not been shown to be very helpful, it does appear that fairly focused and structured counseling can be useful for individuals with Asperger's, particularly when the child is experiencing overwhelming sadness or negativism, anxiety, family functioning, frustration about vocational goals and placement, and/or ongoing social adjustment.

### ***Unproven Treatments***

No drugs are used routinely to treat Asperger's Disorder. Because little information about pharmacological interventions with individuals with Asperger's is available, pharmacological interventions with young children are probably best avoided (Klin & Volkmar, 1995). Specific medication might be indicated if Asperger's is accompanied by debilitating depressive symptoms, severe obsessions and compulsions, or a thought disorder. Pharmacologic interventions may be used to treat co-morbid disorders, including attention problems, mood disorders, dysthymia, bipolar disorder, and obsessive-compulsive disorder (Klin & Volkmar).

Recent studies suggest Serotonin Selective Reuptake Inhibitors (SSRIs) help treat repetitive behaviors, impulsivity, irritability, and aggression (Brasic, 2002). Controlled clinical trials, based on well-diagnosed populations, are needed to confirm the impression that SSRIs and atypical neuroleptics may alleviate core symptoms of Asperger's and related conditions (Brasic). For

further information on the use of SSRIs, see “Antidepressants and the Risk of Suicidal Behavior” section in the *Collection*.

Challenges of utilizing pharmacological treatments for Asperger’s include the possibility that individuals may have difficulty tolerating side effects that would be minor to most people and may have difficulty identifying and communicating to others their internal mood states and emotions (Blacher et al., 2003).

## **Vaccines and Autism**

In recent years, there has been concern expressed about vaccines and their role in the development of autism. It was previously theorized that a link may exist between the use of thimerosal, a mercury-based preservative once used in the measles-mumps-rubella (MMR) vaccine, and autism (National Institute of Mental Health [NIMH], 2007). Although mercury is no longer found in childhood vaccines in the United States, some parents still have concerns about vaccinations (NIMH). Carefully performed scientific studies have found no relationship between MMR vaccine and autism. In May 2004, the Institute of Medicine (IOM) released its final report, which found that thimerosal, a mercury-based preservative once used in vaccinations, had no causal relationship with the development of autism (NIMH). Because signs of autism may appear around the same time children receive the MMR vaccine, some parents may worry that the vaccine causes autism. The recommended vaccination course for all children continues to be two doses of MMR vaccine (Centers for Disease Control, 2007).

## **Activities in Virginia**

In recent years, there has been activity in Virginia to address rising concerns about the Commonwealth’s ability to provide high quality services to children diagnosed with ASD. In 2006, the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services convened a workgroup to review ways to provide a coordinated response to educating and treating of individuals with ASD. The workgroup was continued in 2007. Recommendations for services and support were developed, including a recommendation to establish a central agency for ASD.

In 2007, the Joint Commission on Health Care convened the Workgroup Regarding the Commonwealth’s Ability to Serve Children and Adults with Autistic Spectrum Disorder (ASD). The workgroup’s objective was to recommend a primary agency for developing, coordinating, and overseeing autism services. This agency would serve as the primary entity to oversee the provision of services for individuals diagnosed with ASD. A recommendation was adopted by the Commission to have the Secretary of Health and Human Resources develop an implementation plan to identify the state agency that should be responsible for serving individuals with autistic spectrum disorders, including a recommendation about whether the agency should serve individuals with any or all developmental disabilities.

## **Conclusion**

Early intervention and treatment are the single most important efforts a parent can make to influence the outcomes for a child with PDD. Proper assessment is crucial in the diagnosis and treatment of PDD. With appropriate intervention, many associated behaviors can be modified and effective strategies can be instilled to allow the child to cope with PDD.

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### **Virginia Resources**

#### **Autism Outreach, Inc.**

703-669-4972

<http://www.autismoutreach.org>

#### **Autism Society of America**

Central Virginia Chapter

P.O. Box 29364 – Richmond, VA 23242-0364

804-257-0192; Fax: 804-290-0286

<http://www.asacv.org>

Northern Virginia Chapter

P.O. Box 1334 – Vienna, VA 22183-1334

703-495-8444

<http://www.asanv.org>

#### **Commonwealth Autism Service**

2201 West Broad Street, Suite 107 – Richmond, VA 23220

800-649-8481

E-mail: [information@autismva.org](mailto:information@autismva.org)

<http://autismva.org>

#### **Everybody's Talking**

<http://www.vcuhealth.org/vtcc/everybodytalking>

#### **Parent Educational Advocacy Training Center (PEATC)**

6320 Augusta Drive, Suite 1200 – Springfield, VA 22150

703-923-0010 or in VA only 800-869-6782 —Latino Outreach: 703-569-6200

E-mail: [partners@peatc.org](mailto:partners@peatc.org)

<http://www.peatc.org>

#### **People with Attention and Developmental Disabilities Association (PADDA)**

813 Forrest Drive, Suite 3 - Newport News, VA 23606

888-33PADDA or 757-591-9119

E-mail: [amoore@padda.org](mailto:amoore@padda.org)

<http://www.padda.org>

**Virginia Autism Resource Center**

<http://www.varc.org>

Richmond Office: 4100 Price Club Blvd. - Midlothian, VA 23112

E-mail: [info@varc.org](mailto:info@varc.org)

804-674-8888 x 5162 or 877-667-7771

Winchester Office: P.O. Box 2500 - Winchester, VA 22604

E-mail: [shamsi@varc.org](mailto:shamsi@varc.org)

540-542-1723 x 6405

**Virginia Commonwealth University Health System**

Virginia Treatment Center for Children (VTCC)

Autism Center of Virginia/Assessment Clinic for Children with Developmental Disorders

515 N. 10<sup>th</sup> Street – Richmond, VA 23219

804-828-4725

<http://www.vcuhealth.org/vtcc/index.html>

**Virginia Department of Education**

Office of Special Education and Student Services

P.O. Box 2120 - Richmond, VA 23218-2120

804-225-2402

<http://www.pen.k12.va.us/VDOE/sess>

**Virginia Department of Health**

Child & Adolescent Health, Division of Child & Adolescent Health

109 Governor Street, 8<sup>th</sup> Floor - Richmond, VA 23219

804-864-7685

<http://www.vdh.state.va.us>

**Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services**

P.O. Box 1797 - Richmond, VA 23218

804-786-3921

<http://www.dmhmrzas.virginia.gov>

**Virginia Institute of Autism**

1414 Westwood Road - Charlottesville, VA 22903-5149

E-mail: [information@viaschool.org](mailto:information@viaschool.org)

434-923-8252

<http://www.viaschool.org>

**Virginia Kids**

<http://www.virginiakids.net>

**Organizations/Weblinks****Association of University Centers on Disabilities**

301-588-8252

<http://www.aucd.org>

**Autism and PDD Support Network**

<http://www.autism-pdd.net>

**Autism Research Institute (ARI)**

4182 Adams Avenue – San Diego, CA 92116

619-281-7165

<http://www.Autismresearchinstitute.com>

**Autism Society of America**

7910 Woodmont Avenue, Suite 300 – Bethesda, MD 20814-3067

301-657-0881 or 1-800-3-AUTISM

<http://www.Autism-society.org>

**Autism Speaks**

2 Park Avenue, 11th Floor – New York, NY 10016

212-252-8584, Fax: 212-252-8676

[contactus@autismspeaks.org](mailto:contactus@autismspeaks.org)

<http://www.autismspeaks.org>

**Centers for Disease Control and Prevention**

Autism Information Center

<http://www.cdc.gov/ncbddd/dd/ddautism.htm>

**HealthyPlace.com**

[http://www.healthyplace.com/site/autistic\\_disorder.asp](http://www.healthyplace.com/site/autistic_disorder.asp)

**MAAP Services**

P.O. Box 524 - Crown Point, IN 46308

219-662-1311

<http://www.maapservices.org>

**National Alliance for Autism Research**

99 Wall Street, Research Park - Princeton, NJ 08540

888-777-NAAR

<http://www.naar.org/about/contact.asp>

**National Dissemination Center for Children with Disabilities (NICHCY)**

P.O. Box 1492 - Washington, DC 20013-1492

E-mail: [nichcy@aed.org](mailto:nichcy@aed.org)

202-884-8200 or 800-695-0285

<http://www.nichcy.org>

**National Institute on Deafness and Other Communication Disorders**

31 Center Drive, MSC 2320 - Bethesda, MD 20892-2320

E-mail: [lel@ms.nidcd.nih.gov](mailto:lel@ms.nidcd.nih.gov)

800-241-1044 - TTD/TTY: 241-1055

<http://www.nidcd.nih.gov>

**National Institute of Child Health and Human Development**

<http://www.nichd.nih.gov>

**National Institute of Mental Health (NIMH)**

6001 Executive Blvd., Rm. 8184, MSC 9663 - Bethesda, MD 20892-9663

E-mail: [nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)

866-615-6464

<http://www.nimh.nih.gov>

**National Institute of Medicine of the National Academies (IOM)**

202-334-2352

[www.iom.edu](http://www.iom.edu)

**National Network for Immunization Information (NNii)**

409-772-0199

<http://www.immunizationinfo.org>

**Online Asperger Syndrome Information and Support**

<http://www.udel.edu/bkirby/asperger>

**Pervasive Developmental Disorders Screening**

Test-Stage I (PDDST), Porter Psychiatric Institute

415-476-7385